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# A QUALITATIVE ANALYSIS OF THE INFORMATION NEEDS OF PARENTS OF CHILDREN WITH CYSTIC FIBROSIS PRIOR TO FIRST ADMISSION

## Abstract

**Purpose:** Hospitalization can be stressful for patients and their families. Pre-hospitalization information is crucial in establishing a good basis for patient satisfaction. In order to develop better preparatory material for parents, this qualitative study explored whether parents of children with Cystic Fibrosis, admitted to a UK Children's Hospital, felt adequately prepared for their child's admission.

**Design and methods:** Data were collected from twelve parents whose children had been admitted within the last two years for routine intravenous antibiotics. Semi-structured interviews were analyzed using thematic analysis.

**Results:** Four themes emerged from the analysis: (1) Preparing for admission, (2) The ward as a challenging environment, (3) Changes in the parent-professional relationship and (4) The parental role in medical care.

**Conclusion:** Provision of adequate preparatory information is essential in reducing parental stress, influencing how future experiences are appraised and managed. Effective parent-professional communication and opportunities to participate in care are likely to improve parental satisfaction.

**Practice implications:** Preparatory information prior to hospital admission greatly assists parents in making informed decisions and working as joint advocates in their child's inpatient care.

**Keywords:** Cystic Fibrosis; Information needs; Parents; Intravenous antibiotics

## Introduction

Cystic fibrosis (CF) is a chronic, life-limiting, multisystem disease, affecting more than 10,800 people in the UK (UK Cystic Fibrosis Registry, 2015). Patients with CF are required to complete rigorous treatment regimens comprising of daily physiotherapy, medication and nutritional monitoring (Cystic Fibrosis Trust, 2011; Bishay and Sawicki, 2016). During childhood and early adolescence, parents play an integral role in delivering care and facilitating treatment adherence within the home environment (Butcher & Nasr, 2015; Goodfellow, Hawwa, Reid, Horne, Shields, & McElnay, 2015; Modi, Marciel, Slater, Drotar, & Quittner, 2008). In some instances, hospitalization for more intensive treatment is required. Many children with CF are admitted to the hospital for a course of intravenous (IV) antibiotics (lasting 2-3 weeks), to manage pulmonary exacerbations (Bhatt, 2013; Cystic Fibrosis Trust, 2009; Flume et al., 2009).

It is well recognized that hospitalization is a highly stressful experience both for children and their families (Commodari, 2010; Franck, Mcquillan, Wray, Grocott, & Goldman, 2010; Franck, Wray, Gay, Dearmun, Lee, & Cooper, 2015; Nabors et al., 2013). Parents are required to familiarize themselves with new settings, routines, negotiate new roles in care and manage anxieties regarding their child's treatment (Verwey, 2008). For parents of children with CF, these uncertainties are likely to be especially challenging, given their central role in the day-to-day management of their child's condition. There may be added stress due to in-hospital isolation measures, in place to reduce the possibility of cross-infection (Saiman, et al., 2014; Festini et al., 2006; Griffiths, Carzino, Armstrong, & Robinson, 2004). Evidence indicates that in-hospital isolation is associated with adverse psychosocial outcomes, including feelings of isolation and perceived lack of social support (Duff, 2001; Griffiths et al., 2004; Russo, Donnelly, & Reid, 2006; Visse, Abma, van den Oever, Prins, Gulmans, 2013).

High parental distress has been identified as a barrier to effective participation in child care and can adversely affect the hospitalized child both during (Power & Franck, 2008) and after admission (Dunn et al., 2012; Kassam-Adams, Fleisher, & Winston, 2009; Nugent, Ostrowski, Christopher, & Delahanty, 2007). It is becoming increasingly recognized that informing and preparing parents of what to expect during their child's hospitalization is crucial in reducing distress and enabling parents to maintain a key role in care (Commodari, 2010).

In the UK, the National Service Framework for Children, Young People and Maternity Services (NSF CYPMS; Department of Health, 2003) identified this need and set out standards of care highlighting the importance of providing “accurate information [regarding hospitalization] that is valid, relevant, up-to-date [and] timely” and doing so “utilizing a range of communication methods so that information may be made available regarding specific conditions, medicines and procedures” (Department of Health, 2003, p. 16).

Research has shown that preparatory programs such as the conveyance of detailed information in person, via leaflet or DVD, have the potential to improve the hospitalization experience for both patients and their families (e.g., Buckley & Savage, 2010; Claar, Walker & Barnard, 2002; Gordon et al., 2011; Margolis et al. 1998; Schmidt, 1990; Smith & Callery, 2005).

### *Aims*

This study aimed to investigate the information needs of parents of children with CF, admitted to a UK pediatric CF service for routine IV antibiotic treatment. No research to date has qualitatively explored the preparatory needs of parents of children with CF prior to first admission. This study was designed to address this gap in the literature with specific focus placed on the following questions:

- What do parents need in order to feel adequately prepared for their child’s initial inpatient hospital admission?
- How can the CF pediatric service better meet the needs of these parents, addressing the requirements set out by the NSF CYPMS (Department of Health, 2003)?

## **Methodology**

### *Design*

A qualitative design was employed, through which data generated from semi-structured interviews were analyzed using inductive thematic analysis (Braun & Clarke, 2006). Thematic analysis was chosen as it provides a reflective approach that allows researchers to capture the richness and in-depth nature of participants’ experiences and allows for the generation of general themes across the data set.

98

99 *Participants and recruitment*

100

101 Twelve parent couples were contacted for interview. Parents had been identified by the team's  
102 Senior Nurse and Physiotherapist. Parents were eligible for participation if (i) they had a child  
103 who had experienced their first planned inpatient hospital admission (or first inpatient hospital  
104 admission since infancy) within the last two years and (ii) the admission had been related  
105 to the delivery of IV antibiotic treatment.

106

107 Ten parent couples agreed to take part. Eight mothers were interviewed alone, and two couples  
108 were interviewed together. Parents ranged in age from 35 to 70 years ( $M=45.2$ ,  $SD=9.8$ ), self-  
109 identified ethnicity was as follows: 11 White British and one Asian British. Children ranged in  
110 age from 2 to 14 years ( $M=8.1$ ,  $SD=4.1$ ).

111

112 *Ethics*

113 Ethical approval was obtained from the University of Bath Psychology Ethics Committee and  
114 the Research and Development Department of the local NHS Trust.

115

116 *Semi-structured interviews*

117

118 Semi-structured interviews took place with each parent (or parent couple) who consented. The  
119 questions that formed the interview guide (Table 1) were developed through discussion with  
120 the CF staff team and informed by the current literature and the study objectives. The input of  
121 local (CF team) and international (literature) in the field in informing the questions, the  
122 interview schedule can be stated as having face validity. The purpose of the semi-structured  
123 interview was to systematically collect information from parents by asking uniform questions,  
124 while offering the flexibility for parents to provide additional relevant information and allow  
125 the interviewer to ask clarifying questions.

126

127 [Table 1 is inserted about here]

128

129 Interviews were conducted by the first author and took place within the parents' homes.  
130 Interviews were audio-recorded and each lasted between 45 and 75 minutes.

131

## *Data analysis*

The interviews were transcribed verbatim and analysed using Braun and Clarke's (2006) six-phase guide to thematic analysis. A deductive and inductive analysis was conducted. The deductive analysis specifically drew out quotes relating to the first research question (Theme 1), whereas the inductive analysis developed the rest of the transcripts into themes, thus it was data-driven rather than research question-driven (Themes 2, 3, 4). In this way, it was ensured that the first research question was answered, while allowing an open analysis to answer the second research question

The first author read the transcripts repeatedly to ensure familiarisation with the data. Initial ideas were noted down and the data were then coded. Data with the same codes were collated and sorted into identifiable themes and subthemes. Themes were then refined by comparing the generated themes to the original text and their appropriateness and resonance in relation to the research question were reviewed. To ensure rigor, as suggested by Yardley (2008), a 'paper trail' was kept to identify how themes had developed over time. The above process was completed by the first author alone.

To promote reliability of the analysis, the themes were verified by the third author (JD), an experienced clinical psychologist and researcher within the area of clinical health psychology. The third author independently analyzed four transcripts and then met with the first author to compare findings and reach a consensus regarding the thematic structure. Finally, the fourth author (SP), who had expertise within the area of CF, was asked to review the thematic map and codes as a final credibility check.

## **Results**

Four main themes emerged from the analysis: (1) Preparation for admission, (2) the ward as a challenging environment, (3) changes in the parent-professional relationship and (4) the parental role in medical care. Sub-themes were identified for the first theme only. Themes describe the parents' 'journey' from the clinic to the hospital ward and the associated challenges that shaped their perceptions of the hospital experience. Pseudonyms have been used to preserve parent anonymity.

### *Theme 1: Preparation for admission*

In all cases, admissions took place within the context of routine symptom monitoring. This meant that the consulting CF physician made a decision, following necessary tests and observations, that a hospital admission for IV antibiotics was required.

#### *Suddenness of admission*

All parents described a relatively short period of time (i.e., a few days) between being informed of the possibility of admission and entering hospital. As a result, the admission was perceived as “*last minute*”, leaving little time to prepare for the hospital stay.

For two parents, the lack of time to prepare was positively received as it meant that they had little time to think things through, reducing anticipatory anxiety: “*It was probably better in some ways because your mind isn’t as anxious, and your mind isn’t fully on it, so you can just deal with it*” (participant 10). For some, this perceived suddenness led to feelings of “*shock*” and a desire to deny the prospect of admission. For one parent, the news that her daughter was to be admitted was perceived as altogether “*overwhelming*”, affecting her ability to retain important information about the admission: “*She may have given me information that I wasn’t able to take in at the time because we’d just come out of an appointment where we’d learned she was going into hospital*” (participant 4).

#### *‘Going in blind’*

Although the shock of admission may have impacted upon their ability to take on board what was said, parents unanimously reported that they received minimal preparatory information. For one parent, it felt as if she was “*going in completely blind*”.

Parents noted that information provided was primarily medical and practical in nature, while the “*psychological aspects of the admission were overlooked*” (participant 5). Some parents highlighted that although medical procedures were broached; information regarding outcomes, associated risks and possible side effects of the medication were not discussed prior to admission, leaving them feeling out of control of their child’s long-term well-being. As one mother explained: “*We did not know that one of the antibiotics could cause hearing loss. We thought, ‘This is something else to worry about; they have not told us about this’. We felt we had no control over the situation*” (participant 2).

198

199 Parents highlighted the importance of providing adequate preparatory information. They  
200 reported a need for detailed information regarding the management of their child's condition  
201 (treatment, mechanisms of drug action and potential side effects) and the expected treatment  
202 outcomes. Furthermore, parents acknowledged a need for information regarding the  
203 psychological impact of admission. As one parent explained: "*the emotional preparation is*  
204 *important: being aware of how you are going to feel. It is full of anxiety really; if I went back*  
205 *those first couple of days*" (participant 5).

206

## 207 *Theme 2: The ward as a challenging environment*

208

209 As a consequence of the limited preparatory information, parents reported feeling ill-prepared  
210 for the changes in routine, the sense of isolation and the intensity of the ward setting. As  
211 previously noted, CF is a condition that requires a structured treatment regimen for effective  
212 disease management; parents therefore play a key role in maintaining adherence (Modi,  
213 Marciel, Slater, Drotar, & Quittner, 2008). Some parents reported difficulty adjusting to  
214 changes in routine, noting the "*fluid*" nature of the ward environment and associated lack of  
215 structure regarding medication and treatment delivery: "*There's no set time...you do end up*  
216 *waiting around*" (participant 1).

217

218 The privacy afforded by individual rooms was valued by some, as it allowed for an element of  
219 environmental control to be regained. However, for others, this isolation evoked intense  
220 feelings of isolation, particularly for parents of younger children: "*it is nice because you have*  
221 *your own room, but at the same time you're a bit isolated...having a young child this was*  
222 *particularly the case as you have to be with them all the time*" (participant 3). Whilst some  
223 parents acknowledged the importance of isolation measures in reducing the chances of cross-  
224 infection, other perceived these measures as punitive. One parent, whose child was 20 months  
225 at the time of admission, compared the room to a "*prison cell*" in which she felt "*trapped*".

226

227 The ward environment was described as "*light*" and noisy, with frequent disruptions taking  
228 place throughout the night. These environmental factors were associated with feelings of  
229 exhaustion, as one parent explained: "*there was no let-up...it just felt 24/7*" (participant 6).

230



Some parents spoke of the emotional impact of being on the ward and the difficulty in seeing sick and vulnerable children. One spoke of her distress in seeing an older child with CF, which aroused her own fears regarding the future: *“you meet parents of older children with CF...that was quite scary because ... you realise that you are in the same boat as people in a really really difficult situation and that can be quite alarming”* (participant 4). These feelings were echoed by another parent who described the ward experience as a *“reality check”* raising awareness of the fact that her child had a serious chronic condition that could result in multiple hospital admissions.

A couple of parents recommended a pre-admission visit to the ward in order to build familiarity with the setting and therefore decrease anxiety: *“I think it would be useful to have a light hearted informal visit to a ward, which I think would manage the fear and help you know what is coming”* (participant 6).

### *Theme 3: Changes in the parent-professional relationship*

Admission to the ward brought with it not only a change in environment and routine but also a change in staff team. As with other aspects of the admission, parents reported feeling unprepared for this change. As one parent explained: *“I’m so used to seeing my team, the cystic fibrosis team, and when we went in there I thought: ‘Why are they not visiting today?’”*(participant 7). Parents reported a trusting and supportive relationship with their community CF team, having known them since their child’s diagnosis; one parent referred to them as *“family”*.

This contrasted with the less individualised approach to care on the ward, with some parents feeling that senior professionals did not listen to them, provide clear information regarding their child’s treatment status or fully appreciate their anxieties regarding their child’s admission. As one parent put it: *“I felt there was a slight tendency for staff to regard as routine what is actually an enormous upheaval for a family, particularly when you don’t know the ropes”* (participant 4).

The need for more open communication between senior physicians and parents in allaying anxiety and fostering trust was raised in several interviews. Also identified was the importance of highlighting to parents the changes in care teams prior to admission: *“To be confronted with*

*a different team is a bit of a shock. I feel it is important for parents to know this so that they can prepare themselves and adjust their expectations accordingly”(participant 1).*

#### *Theme 4: The parental role in medical care*

All parents spoke of their need for involvement and participation in care. This theme describes the juxtaposition between two parental roles: active participant and passive observer. Lack of preparation and poor communication with senior ward staff left parents feeling disempowered and unsure of their role in care. For most parents, feeling in control was important; they perceived themselves as experts in their child’s care and thus wanted to maintain a sense of “*autonomy*”.

For some parents, feeling as though they had to relinquish control to the medical team was perceived as “*frustrating*”. As one parent put it: “*I felt like: ‘I am her mum; I should be doing these things’*” (participant 2) . For others, a lack of clarity regarding their role on the ward led them to believe that their role was now redundant: “*it gets taken out of your hands, you feel a bit useless*” (participant 3). The ability to regain control came more easily to some than others. One parent found that communication and knowledge of the situation were fundamental in bringing her round to hospital life: “*I felt I wasn’t in control and I think some of the things that I have done have brought back that control a little bit. Just making sure that I felt that I understood everything that was going on and having people around me that I could trust and rely on and speak to about how I felt*” (participant 9). For another parent, learning to administer IV antibiotics and working closely with the staff team allowed her to take back some responsibility: “*We felt a cohesion to the team rather than just being a lump sitting there in the corner, regretting that our child was in hospital and not being able to do anything to make it better*” (participant 4). For one parent, however, taking “*a step back for a little while*” was seen as the appropriate response.

Given their lack of preparation, most parents reported a desire for further information and knowledge: “*I like to know because I think I like to maintain as much control as possible. When you’re the parent of a child with CF you get used to taking an active role in their care*” (participant 11). One parent spoke of her stress in not knowing: “*I think as parents...you regard it as a very long-term commitment to their health so you want to be as knowledgeable and*

*involved as possible. The worst thing is being half involved and half knowledgeable”*  
(participant 4).

## **Discussion**

Hospital admission can be a daunting prospect for patients and their families. Current health policy promotes the need to inform parents of what to expect during their child’s hospitalization in order to allay fears and increase active participation in care (Department of Health, 2003). The findings of this research indicate that the majority of parents felt unprepared for their child’s hospital admission, specifically, they reported a short time frame between being notified of admission and entering the ward. Furthermore, information was considered limited, addressing certain practical and medical aspects of admission, with minimal emphasis on the psychological and social implications.

Parents reported how inadequate preparation had an adverse impact on how they experienced their time on the ward. They reported feeling ill-prepared for the changes in the environment, routine, and staff team, resulting in anxiety, uncertainty and distress regarding their role in care. These findings support previous research that indicates hospital-related distress among parents of hospitalized children, especially during times of significant uncertainty (Kassam-Adams et al., 2009). Parental distress has been identified as a barrier to effective participation (Power & Franck, 2008) and has been shown to impact negatively on the hospitalized child (Dunn et al., 2012; Kassam-Adams et al., 2009; Nugent et al., 2007).

Evidence has shown that in such situations parents will often seek to reduce their anxieties by improving their knowledge of their child’s treatment and negotiating new roles in care (Corlett & Twycross, 2006). For some parents in this study, forging new relationships with staff and actively seeking out opportunities to facilitate in care led to a positive hospital experience. However, most of the parents were unclear what medical staff expected of them and report that this was never clearly communicated, and so they felt limited in their capacity to actively participate in the care of their children. These findings highlight some of the challenges associated with implementing a ‘family-centered care’ approach (Shields, Pratt, & Hunter, 2006) within routine clinical practice.

Parents reported that they would have appreciated timely, detailed and comprehensive information, addressing the full range of medical, practical and psychosocial implications of

admission. In so doing, parents felt that they would be better equipped to cope with their child's hospitalization, adjusting their expectations accordingly and effectively preparing for admission. Indeed, parental satisfaction with their child's medical care has been found to be closely associated with their perception of adequacy of information provided (Kvaerner, Moen, Haugeto, & Mair, 2000; Magaret, Clark, Warden, Magnusson, & Hedges, 2002). Melnyk (1994) showed that parents who were informed about their child's expected behaviour and their own optimal role were significantly more supportive during their child's intrusive health-care procedures.

### *Implications for clinical practice*

This study provides a valuable insight into parent's experiences of their child's initial hospital admission and has important implications for clinical practice. A key message arising from the interviews was the parents need to be perceived as joint advocates with clinicians for their child's care, comfort and improved health. This fits with their perceived role as both 'parent' and 'carer'<sup>1</sup>, having developed expertise in the management of their child's condition (Modi et al., 2008). Health care professionals have a role in assisting parents to make informed decisions and to retain a sense of control over their child's treatment. In order to facilitate this, there is a need for parents to have access to sufficient preparatory information prior to admission (e.g., in the form of a leaflet or DVD) and to have the freedom to openly discuss their concerns regarding their child's healthcare during the hospital stay. The findings of this research support the recommendations set out by the UK NSF CYPMS (2003) and are in line with European and US best practice guidance that highlight the importance of effective information and communication in CF care (Smyth et al., 2014; Mogayzel Jr, Dunitz, Marrow, & Hazle, 2014). This paper advances our understanding of the specific needs of the parent of the CF child, and can be used to inform the delivery of best practice guidance in both the UK and on an international level.

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<sup>1</sup> In the UK, the Carer's Trust defines a carer as anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

## *Limitations*

Ninety-two percent of parents interviewed were White British which may limit the generalizability of the findings to other cultures or ethnic groups. A common critique of studies regarding parental experiences is the lack of fathers' views (Noyes, 1998). While the aim of the present study was to gain a general understanding of parents' concerns, the vast majority (83%) of parents who participated were mothers. It is possible that different issues would have emerged if a greater number of fathers had participated, this would be an interesting area for future research.

## *Conclusion*

The findings of this study illustrate the importance of adequate preparatory information in reducing parental stress and influencing how future experiences are appraised and managed. Information must address all aspects of admission including the medical, practical *and* psychosocial implications. Effective parent-professional communication and opportunities to participate in care will improve parental satisfaction.

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## **Conflict of interest statement**

The authors have declared that they have no competing or potential conflicts of interest.

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- Tell me about your child (age, health)
- Tell me about your child's first hospital admission for IV antibiotics
- What preparatory information/advice did you receive?
- How and when was this information given?
- Do you feel it was provided in a timely fashion?
- What information/advice did you find most helpful and why?
- What information and/or support did you not receive that could have been helpful?
- When would you like to have received this information?
- What effect did this preparation/ lack of preparation have on the admission experience?
- How could staff best prepare parents for their child's first admission?